

Newsletter of the Spastic Paraplegia Foundation



How to Help

We operate out of the strength of our community, caring friends and sponsors. Your help makes a difference!

Please contact us at volunteer@sp-foundation.org to help in one of the areas below or to suggest another way you can get involved.

Support Research to Speed Our Cures by Volunteering

Below you'll find information on some of the ways you can help SP Foundation in their search for a cure to PLS and HSP.

Raise Funds: The primary focus of SPF is to raise funds to support research to find the causes, treatments and cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. Our major fundraising activity consists of a TeamWalk. Individuals can help organize local fundraisers. People are also needed to secure corporate sponsorships and help with grant applications.

Patient Connection Programs: Organizing a Connections gathering for people to meet, share stories and help one another is a great service. Events can be as simple as meeting for coffee! In areas with large patient populations, SPF seeks to establish Chapters.

Conference Organizers: The SPF seeks event coordinators in or near metropolitan areas who can work with us to organize Conferences for our community. These events feature speakers and programs on special topics of interest to our community as well as provide the opportunities for individuals to meet others. Conferences can be half-day or full-day events.

Communications: Individuals with writing, research, website or graphic design skills are needed to assist with various communication initiatives.

Ambassadors: Ambassadors raise awareness about our disorders as well as enhance community building and industry relationships. You can assist with media relations, share your story, speak at local groups or help with grassroots advocacy.

Business and Administrative Support:

Volunteers with business and administrative skills can play a valuable role in administering the work of the SPF. Most of the help is coordinated through email correspondence and uses popular Office applications.



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The Spastic Paraplegia Foundation Inc. (SPF) is a national, not-for-profit, voluntary organization. It is the only organization in the Americas dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP).

Synapse Editor

John Staehle.....Senior Editor

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Letter from the President



Dear Friends,

B efore you begin reading the many interesting articles that our editor, John Staehle, has put together for this issue of *Synapse*, I am excited to bring you up to date on where our Foundation has been, where we are now and where we are going.

You will soon be receiving our Annual Report where you'll read all about what an incredible wealth of knowledge our research is developing about HSP and PLS. You will also read about how our finances are carefully and rigorously managed with the

help of our volunteer CPA, David Lewis.

This incredible, mind-boggling, scientific progress toward finding a cure for HSP and PLS is only possible because of you. We are so incredibly grateful to you for your generous 2013 donations. You even surpassed our "Match my Gift" goal of \$80,000. Congratulations and - Thank You So Very Much!

It is the time of the year when hundreds of scientific research proposals previously requested from thousands of scientists worldwide are about to be turned in. Mark Weber, our volunteer attorney and founder, works tirelessly on this project. Our Scientific Advisory Board (SAB) of world-renowned neurological experts will soon donate their time and expertise to rank these proposals, making certain we are funding the very best research.

Yet, for every research study we can afford to fund, there are five others that our SAB ranks as equally very promising but that we cannot afford: What are we leaving undiscovered? What other facts can we learn this year that very probably could make all the difference for your friends and family who suffer every day? By the end of June, we need to know exactly how many studies we can afford to support and there's always room for more so please help if you can!

The theme of our SPF Annual Conference this June 13-15 in Dallas, TX will be "Rounding up a Cure." With this in mind, I want you to please "grab a hold of the reins" by doing three things: First, please add to your calendar and register on our website for the SPF annual conference.

Second, please find the email address of the SPF State Ambassador nearest you on our website to find out what is going on in your area and get involved -- we cannot do this without you. Third, please

mail whatever tax deductible donation you can in the enclosed envelope. Every dollar is one step closer to a cure. Convenient "Monthly Giving" and "Planned Giving" Programs are also available at <u>SP-Foundation.org</u>.

It is only because of *you* that such amazing progress is taking place toward finding a cure or treatment. Thank you again!

Sincerely,

Frank Davis
President, SPF

PS - Put our 2014 Annual Conference on your calendar! It will be in Dallas, June 13-15. More information about the location and how to register will be on the website soon.

Important Things to Know About Getting a Service Dog

By Mari White, Kansas State Ambassador

There is a lot of thought that needs to be put into getting a service dog but benefit is a lifelong friend that becomes in tune with you as a person. Once the bonding takes place, these dogs become an extension of you and can do so much to help.

A person planning on getting a service dog needs to anticipate a wait time of up to two or three *years* to make it through the process. So the sooner they get on the list, the sooner the training organization can start looking for the right match. A lot goes into that decision.

A legitimate organization takes into consideration your personality, your city, your living arrangements, your mobility needs, your support system, and several other things. Then they look at the personality of the dog,

the health, the size, and what the dog has been exposed to training wise. If they know that you are one that goes out into the community or travels a lot or goes to the theater, they will work with the dog to acclimate the dog to those situations.

Each organization is a little different as to how they train the dogs. Some use only certain breeds or certain pure breeds and work with an international breeding program to ensure

quality. Others work with shelter dogs and other mixed breeds. Some train exclusively in the community and some use prisoners to help train the dogs. Some charge and some have grant funding for the cost of training and do not pass that cost on.

Typically, a dog will start training as a puppy in the community at eight weeks old with what they call a puppy raiser. These are individual families that do basic obedience and will work with people skills in the community. Many take the puppies to work.

At this point no one knows if the puppy will actually make it to the final program. A legitimate program will be watching growth, eyes, hips, etc. and personality to see if they will be better at being a mobility dog, a therapy dog, a guide dog, a seizure or diabetic dog, etc. Dogs can be trained for all kinds of medical issues, even post-traumatic stress for the veterans.

Puppy trainers typically work with the puppy for about 18 months. Once they reach 18 -20 months, the puppies are returned back to the training facility for essentially college level training where they work with wheelchairs, kids, crutches, stairs, retrieving things, etc. They usually do this for at least six months. Throughout this time they continue to be studied.

If they pass all the necessary tests then the next phase is meeting the potential owner and a rigorous two weeks of individualized training. If all goes well and the final test is passed, then the person gets to keep the dog and they

then start training in the home of the individual. Typically, an agency will continue to work with and support you for over a year before they finally release all responsibility and ownership of the dog. A good agency will continue to be involved and help, where necessary, as problems come up for the life of a dog and they will help with issues of retirement of the dog, too.

On average, it costs upwards of

\$30,000 to train the dogs. Many community agencies like the Lions Club or Kiwanis Clubs or Optimist Clubs will help cover the cost of a dog. Many times the new partnership can do volunteer work for the agency which becomes a win-win for both the agency and the dog. It gives exposure and practice for the dog and it gives identity to the agency when the public sees a well-trained team.

In our area, we have what is called puppy training which is a support group of all puppies in training in that area and they get together to train and to socialize. We take the service dog to that as a role model and as a social group and its good practice even for the older service dog.

Continued on next page





A legitimate organization will belong to the International Service Dog Association (ISDA) and will use their testing curriculum in making sure the dogs are ready to work in the public. Follow up is incredibly important. An agency should be willing to be available after the placement to guide and help where necessary as problems crop up. There is no way a dog can be 100% trained to each individual before the match. It takes

time. Being available for support is very important.

Some agencies have a facility with dorms or duplexes where you go and live for two weeks during the training and some will train with you in your home community. Some do both. We trained for two weeks with the first dog, and my son did a week of one on one training with the second dog at their facility. The trainer then came to his school and spent a day or two working with the school and answering questions. She is also coming back in the fall and working with the junior high when he transitions to the new school.

Some agencies work with all kinds of service dogs. Others primarily do mobility, guide or therapy. Not all agencies work with children and this is really important because with kids the training and the dog has to be customized for kids. Our son went on the waiting list when he was 7 and got his first dog when he was 9.

After he lost his first dog to an unfortunate accident, he just got his second dog at 11. It will take approximately 18 months to really, truly bond with a dog so that the dog can think for you. Training goes over just not the mobility needs but also care for the dog. With children, parents have to understand how to not get too involved because the dog needs to know who the "boss" is and know who to bond with. It is frustrating to see our son struggle sometimes but it is very early on in this new relationship.

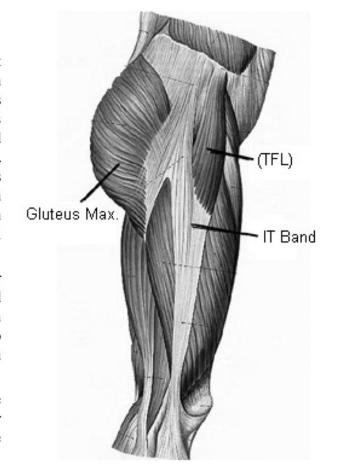
Exercise and You

How to Stretch IT Bands

I have heard so many of us complain about sore hips at night. Here are a few things to help with that. Much of the pain that I experience from the sore hips at night is from having tight IT Bands. What are they? On our hips they are large outer coverings of connective tissue around the hips. I stretch before bed and then do it during the night. The tightness seems to wake me many nights. I am always relieved by stretching and fall right back asleep. You can stretch right in bed. It doesn't even wake my husband when I do this. Here is a picture of your IT Bands or illiotibial bands.

I stretch these by pulling my knee up to the chest and over to the opposite side. That is while lying in bed. Before bed I do butterfly stretches. Some people roll on a special foam roller for stretching your IT bands. There are many ways to stretch them. Just search "IT bands" on the Internet and you will find something that works for you.

Also strengthening exercises seem to help a lot with the tightness and discomfort of these bands. Doing stair steps or side stair steps helps. It seems the more exercise I have the better the less tightness I have.





SPF ANNUAL CONFERENCE 2014 ITINERARY

Dear SPF Family,

Here is the itinerary for the upcoming 2014 Conference in Dallas, Texas, June 13th-15th. Please keep in mind that the times are approximate and could change a little by the time the conference date arrives. At this time, we have not finalized the speakers agenda; however, we have lined up some incredible speakers this year: Dr. John Fink, Professor of Neurology at the University of Michigan; Dr. Mauricio Delgado and Dr. Jonathan Rios, Texas Scottish Rite Hospital for Children in Dallas; Dr. Nazem Atassi, Assistant in Neurology at Massachusetts General; Dr.. Hiroshi Mitsumoto, Professor of Neurology at Columbia University; Rebecca Hart, Para-Equestrian Champion; Corey Braastad, PhD, Athena Diagnostics, Cory Weiser, MetLife and SPF Board Member and Secretary, Jean Chambers with her co-star service dog, Annie.

There will be a silent auction again this year. If you have anything you would like to donate to the auction, please let me know. If you donate a gift card it would be preferable if it is with a store that covers all of the U.S. due to the fact we have so many different states represented. If you have connections with companies or stores that would like to participate, their donations will only add to the auction this year. Also, this year to make it easier on anyone who would like to buy something from the auction, but find it difficult to take it home on the plane, Frank and I will donate free shipping so you can shop without worrying about how to get it home. We want to gradually have the silent auction grow in size and make money for the organization, but this is a process that does take time to develop.

On Saturday attendees will be on their own for dinner. I do know last year quite a few people just stayed around the hotel and visited with each other. Grapevine has lots of incredible restaurants. If you would like try a new venue for dining with some friends, the hotel has a shuttle that will take you to

the restaurant and pick you up when you are ready. The Gaylord Texan is very close by and for those that do venture out, it is a great place to check out. I will try and get names of restaurants posted ahead of time so you can make reservations if you would like to plan ahead.

For attendees that will be flying into Dallas Fort-Worth (DFW), there is a hotel shuttle that will pick you up at the airport and bring you to the hotel. You just have to call when you arrive.

If you have any questions, please feel free to email me and let me help you. If I do not have the answers, I will find out the information you need. I do want everyone who attends to have such a wonderful time. If you have not already registered, please do so as soon as possible. It helps the Conference planners do their job. Many thanks and I look forward to seeing everyone at the 2014 Annual Conference!

Claudia Davis

Rounding Up a Cure 2014 SPF Conference Coordinator (956) 454-5837

Synapse Appeal

Please use the enclosed envelope to make a donation. Thanks to everyone who donated in 2013 to help offset the printing and distribution expenses.

Support SPF with One Step a Month

Consider making a monthly donation to help SPF move a step closer to a cure. Our One Step a Month Program is a win-win! Recurring gifts allow us to plan ahead with confidence, making sure we take the best steps towards finding the cures for HSP and PLS. Plus, recurring donations allow you to give in a convenient, safe and secure way. http://www.sp-foundation.org/donate.htm







SPF ANNUAL CONFERENCE 2014 ITINERARY

Friday,	4:00 PM	Registration and vendor set up at the DFW Lakes Hilton in
June 13	5:30-6:45 PM	Grapevine, Texas. Welcome reception with a cash bar and Texas style appetizers.
	7:00-9:00 PM	Dinner (a cash bar will also be available). During dinner our keynote speakers will be Corey Braastad, PhD, Athena Diagnostics and Cory Weiser, MetLife.
Saturday, June 14	7:30 AM	Continental breakfast will be available. Vendor booths will be open.
	9:00 AM- 12:00 PM	Conference begins with greetings, introductions and the morning's presentations.
	12:00-1:30 PM	Lunch will be served. There's additional time allotted so you may enjoy the vendors' booths. They will be offering some great information for the attendees. Please support our vendors with your time.
	1:30-4:00 PM	Continuation of speakers for the conference.
	4:00-5:00 PM	Breakout sessions begin. There will be three concurrent sessions: Dr. John Fink, SPF Medical Advisor, will host one; Texas Scottish Rite Hospital for Children will host another for parents with children that have HSP or PLS; and Linda Gentner, SPF VP, will host the third session where participants can share experiences, catch up with old friends as well as make new ones.
Sunday, June 15	9:30 AM	Bus will leave for AT&T Stadium (formerly Cowboy Stadium) for the "Team Walk." The stadium is a fun place to tour (even if your favorite team is in another state). We will finish on the field at the end for pictures both as a group and individual photos. The stadium tour starts at 11:00 AM and takes approximately two hours. The stadium tour guides and staff do an excellent job accommodating those with disabilities. You will have time on the field for pictures, both group and individual, before we return to the hotel between 2:30 and 3:00 PM.





up Close and Personal

Just Being There...

By Allen Bernard

When my daughter was diagnosed three years ago with HSP, I had no idea what to expect. As a first-time dad it was hard enough just getting used to the idea of having a two-year-old. To be told she would walk but never like other the kids is an experience that is hard to explain.

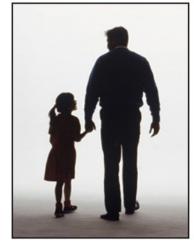
Since that horrible day, things have changed a lot and now I try to just focus on being a dad. Sure I think about HSP every day: how it limits my daughter in some ways but also how lucky we are. I know it sounds odd but Brianna is special. Infant onset HSP is far more like spastic diplegia CP in that it is, more or less, static -- what you are born with doesn't change.

Because of this, I've been able to move away from looking for every little change in my daughter's disability and can instead just focus on raising a child that is at once challenged physically but more than makes up for it intellectually. Based on her high scholastic test scores and her almost negative physical ones, I have an "average" child ... just what I asked for when I learned we were pregnant. (Be careful what you wish for, I guess.)

Sure we have days where HSP limits what we can realistically do but we still go to the playground and sledding and horse back riding. She swims and does gymnastics. Sure it makes me angry and sad (at the same time) sometimes when my daughter can't keep up with the other kids. This is getting a little better as she gets bigger and the world gets smaller but her school mates still run circles around her and it hurts to see that; especially when she cries saying "They all run away." Still I try not to dwell on it. What my little girl needs is a dad who can help her see her possibilities, not her limitations -- those are obvious enough.

I actually take my cues from my daughter. She rarely, if ever complains about her condition. She's too young to ask what she thinks about it, but I guess when you're born with something you can't change you just deal. She's a bright happy little kid. She goes to birthday parties, has friends, has her favorite things, loves to play and draw and do all the things all kids love to do.

She's always showing me something new she can do and, even though the hop isn't has high or her stride isn't as long or her dancing involves a couple of tumbles along with her pirouettes, it doesn't matter. To me, she's doing what all kids do and I'm just as proud as I can be because every jump, every step, no



matter how minor, is a victory over HSP, not a limitation imposed by it.

Understanding Disability

by Brenda Asbury

- It's not about intent, it's about interpretation.
- From a legal standpoint, that's the bottom line.
- From a moral, ethical, professional belief system, when you pity people, you dis-empower them.
- It's not right to take away someone's choices.
- If they can't do it, they'll let you know, otherwise, you have to respect both them and the law.
- Good intentions can still make people feel terrible.





My Kids Aren't "Broken"

By Mari White, Kansas State Ambassador

I wanted to write something that was geared toward parents of kids with HSP (or any neurological disorder for that matter). I am no expert, only a parent, but I have learned so much from my kids who I both admire and love.

My journey of self- discovery and advocacy started 17 years ago when I heard the doctors tell me that my son had Asperger's syndrome, which is a form of autism. I was a single parent at the time and working full time as a nurse. I learned a great deal from him about the importance of believing in oneself and not being afraid to live in the moment.

My son has no fears or worries. Life is what it is and he does not compare himself to some artificial norm. He is who he is and that is that. I wish I could be that confident and not really care what others think. I started advocating for him and learning the hard way how to advocate for my son, including a whole new vocabulary.

Fast forward 17 years and now he is 22 and just about ready to venture out on his own. He is a college student and doing well. I still worry and I still advocate for him but I have learned the whole concept of team work. I learned a lot from Ben.

During this complex ordeal, Alex came along and he has HSP. By now I am much more comfortable in knowing what to ask for and how to pull together a team. If anything I learned to trust my gut and I learned to just ask about everything. The worse anyone could say was no. I also learned to let my kids lead the way and to trust them. This is hard for me but now I just go with the flow and trust in their strengths -- not their weaknesses. I never focus on those.

As far as they are concerned and as far as I am concerned, they are not "broken" and do not need to be fixed. I have taught them that just because they think different or walk different does not make them bad or defective. I never deny them the chance to try things, even if they fail or can't do it. At least they can say they tried. I set the bar high for my boys and I want them to find the path to a meaningful career and independent life.

As far as resources for kids, you just need to ask and listen. I have procured a list of wonderful places to start and each location should glean something for you:

- 1. Your local library. Give them the love of reading and exploring. I can't speak to all libraries but ours has fabulous year round programs for all ages, especially summer fun. These are free.
- 2. Your local zoo or nature discovery center.
- 3. Challenge Air. This is a national program allowing children with any kind of disability from age seven to 21 a chance to fly a real plane as well as learn science and have a ton of fun. It is entirely volunteer run and pilots come from all over and donate their planes for the day.
- 4. Mid-America Games is a big para-Olympic organization of adaptive sports for kids and adults with disabilities. They also bring in speakers from the actual Paralympics and they put on all kinds of events for a three day event every May.
- 5. Muscular Dystrophy Association (MDA) has a phenomenal camp program for kids with all kinds of neuromuscular disabilities. MDA also offers free clinics and other resources depending upon where you live. Some states allow HSP under the umbrella and some don't. (You can advocate and fight if your locale one does not. That is how we got Kansas to accept HSP. I simply asked if why they accepted PLS and ALS why not HSP since they are all in the same family.)
- 6. Angel Flight is an organization that flies kids (and parents) free to medical appointments and camps. They are a national organization.
- 7. Mercy Medical is another organization that flies for free.

When Alex was little he did all kinds of tumbling and gymnastics. It was not competitive but just a bunch of kids rolling around and having fun. Now he does theater, orchestra, and scouts.

The bottom line is to find out what your children enjoy and go with it. Just because they have weak legs does not mean they can't participate in things like debate

Continued on next page





team or write or lead groups. We have also done horseback therapy which really helps the muscles and balance. He also finds that playing on the trampoline and playing Wii Fit sports is a fun way to be with his friends and work on his balance. We incorporate as much neurotypical activity as possible. Swimming is another fun activity.

Other things that have proved to be fun is Space Camp out of Hutchinson Kansas at the Cosmosphere. This is a fantastic program. It is a little more costly but well worth it. Other camps include music and orchestra camps, theater camps. By allowing my kids to live a full and active life and to test the waters and to fit in where possible and to find their greatest gifts they have a chance of growing up not seeing the disability but seeing who they really are -- just like every other kid out there.

It matters not that they are different. I remind Alex about the book *A Wrinkle in Time*, the planet where everyone is a robot and everyone is the same. He agrees *that* life would be awfully boring.

There are Herbal Remedies for Muscle Spasticity

By Tracey Roizman, D.C.

Muscle spasticity is a condition in which muscles are maintained in a state of tension by motor commands coming from the brain. A variety of herbs have shown muscle relaxant properties and calming effects on the nervous system that may help alleviate tight and sore muscles due to muscle spasticity. As with any remedy, consult your doctor before using herbs to treat a medical condition.

OREGANO

Some forms of muscle tension can result from too much oxidation, according to Mary Harwell Sayler and Lori Siegel, M.D., authors of *The Encyclopedia of the Muscle and Skeletal Systems and Disorders*.

When this happens, take extra antioxidants, preferably in the form of fresh fruits, vegetables and herbs, to help reduce the oxidative burden in overworked muscle cells. Many herbs offer powerful antioxidant benefits, some in far greater concentrations than fruits and vegetables. Oregano, for example, contains more antioxidant activity than vitamin E. Other high-antioxidant herbs include bay, dill, coriander thyme and rosemary. Talk to your doctor about using oregano to help your symptoms.

ARNICA

A homeopathic preparation of the herb arnica may alleviate the discomfort of sore muscles, says Adriane Fugh-Berman, M.D., author of *The 5-minute Herb and Dietary Supplement Consult*. Arnica is a member of the daisy family and is also known as wolf's bane or mountain tobacco. This plant is poisonous in regular doses but safe in homeopathic doses.

Arnica has been shown to reduce inflammation, and improve blood flow to injured or bruised muscles. Fugh-Berman also notes antibacterial and antifungal properties of arnica, which can also help relieve muscle soreness that may be related to an infection. Consult your physician about arnica.

BROMELAIN

The enzyme bromelain, found in fruits such as pineapples and papaya, speeds muscle healing from minor injuries by digesting and dispersing the products of inflammation, according to Judith Deutsch, author of the book *Complementary Therapies for Physical Therapy: a Clinical Decision-Making Approach*. You might notice less muscle pain and swelling when you use bromelain. Deutsh also recommends the herb horse chestnut for muscle sprains to bring down swelling. Speak with your physician first.

KAVA KAVA

Kava kava, a Fijian herb may alleviate chronic muscle pain, says Gary Null, Ph.D., author of *The Complete Encyclopedia of Natural Healing*. Kava has been used to treat anxiety and other tension-related disorders. The University of Maryland Medical Center cautions that kava kava may cause liver damage. Take kava kava only under your doctor's supervision.

Chinese herbal medicine also offers relief for muscle tension and soreness. Tian ma gou teng yin, also known as gastrodia and uncaria, and tian ma mi huan su can relieve muscle spasms and lower blood pressure.

Ask your health care provider about these treatments.







2014 ANNUAL CONFERENCE REGISTRATION FORM

Friday, June 13

Texas Welcome Margarita Bar and Appetizers Texas B.B.Q Blue Plate Special Dinner

Saturday, June 14

Speakers include:

Dr. John Fink, Director Neurogenetic Disorders, University of Michigan Dr. Mauricio Delgado, Director of Neurology, Scottish Rite Hospital, Dallas Corey Braastad, Ph.D, Athena Diagnostics

Dr. Jonathan Rios, Ph.D, Staff Scientist, Scottish Rite Hospital, Dallas, TX Rebecca Hart, 5 time USEF National Para-Olympic Equestrian Champion Jean Chambers, Secretary for SPF Board of Directors

Three fun and incredible break out sessions to look forward to also!

Sunday, June 15

Sunday Team Walk

Location still waiting for confirmation (but it will be wonderful)!

Friday Night Dinner \$50.00

Children (12 & under) \$10.00

Saturday Conference \$70.00 (Plated lunch and snacks included)

Children (12 & under) \$10.00

Sunday Team Walk \$20.00 per person (transportation included)

You may register online with a valid credit card. REGISTRATION ENDS JUNE 1, 2014!

Hotel reservations for the Hilton DFW Lakes, call 800-984-1344. Please contact claudiadavis6@yahoo.com with any questions.

Name #1:	Disorder: HSP PLS SP
Name #2: Name #3:	
Child/ren Name: Age: Name: _	Age:
Address: City:	ST: Zip:
Phone: Text: Y/N E-mail:	
I will be using a: Cane Walker Scooter Wheelchair_	·
Friday Night Dinner: Number adults attending: @ \$50.00 per person =	Special Meal Requirement:
Number children attending: @ \$10.00 per person	n = \$
Conference: Number attending: @ \$70.00 per person = \$	SoftGluten-free
Number children attending: @ \$10.00 per person	n = \$
Team Walk & Tour: Number attending: @ \$20.00 per person = \$	(transportation included)
SPF Donation: \$ Payment Type	e:CheckCredit Card
Total Enclosed: \$	lasterCard DVisa
Please make checks payable to SPF . Mail registration forms and payment to:	rd No.:
Francis Davis, SPF President Expil 5305 Miramar Lane	piration Date:
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